DOCUMENT RESUME

ED 302 979 EC 211 866

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TITLE Training Parents of Developmentally Delayed Children in Rural Areas.
PUB DATE 88
NOTE 35p.
PUB TYPE Reports - Descriptive (141) -- Viewpoints (120)

EDRS PRICE MF01/PC02 Plus Postage.
DESCRIPTORS Community Services; Cost Effectiveness; *Delivery Systems; *Developmental Disabilities; History; Infants; *Parent Education; Parenting Skills; Preschool Education; *Program Effectiveness; Respite Care; *Rural Environment; Rural Family; Young Children
IDENTIFIERS *Early Intervention; Education of the Handicapped Act Amendments 1986

ABSTRACT

The report describes the program philosophy and accomplishments over the past decade of the Infant and Early Childhood Intervention Program (IECIP) of the Kansas University Affiliated Program (KUAP) at Parsons, Kansas, which has focused solely on delivering information and training to parents of developmentally delayed children. Topics discussed include the demographics of rural Southeast Kansas, the history of IECIP, basic premises for working with parents, program approach, practical approaches to parent training, and a description of IECIP services and support programs, including a respite care program. The IECIP program is compared with other programs along such parameters as personnel, services, acceptance criteria, cost per client, frequency and length of visits, and degree of program structure. The report concludes with a position statement which holds that early intervention and special education teachers and therapists who provide direct services to children simply cannot achieve the success that parents themselves can achieve in training developmentally delayed children. Furthermore, the report criticizes the proliferation of traditional, center-based preschools in response to the recent passage of Public Law 99-457, the Education of the Handicapped Act Amendments (1986) noting that the same systems now observed to be failing older developmentally delayed students will soon be implemented for children birth to 3 years of age. (JW)

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Training Parents of Developmentally Delayed Children in Rural Areas

Physical and behavioral development of normal infants is very rapid during the first three years of life. During this period, normal infants progress from neurologically immature organisms with primarily reflexive behaviors to almost neurologically mature children who are able to walk, run, perform basic cognitive tasks, and communicate with others verbally in the language of their community.

Precisely how this development is affected has been a subject of controversy over the past years. Some hypothesize that there are critical periods during which inadequate experience can lead to permanent disabilities. Others hypothesize that almost any single event can be overcome with appropriate later experiences (Yarrow, Rubenstein & Pedersen, 1975).

Recently, research suggests that the effects of events and experiences are cumulative (Nielsen, Collins, Meisel, Lowry, Engh & Johnson, 1975). No single adverse environmental condition or experience leads to deficiency; ratner, the cumulative effects of numerous adverse conditions do. There is also the implication that early experiences may be more important to some groups of children than others. For example, it may be more important for neurologically damaged infants to receive optimal levels of experience than infants without such damage.

If the teachers and therapists of developmentally delayed (DD) children were to describe the learning characteristics of the children we work with, we would probably agree on many of the following.

First, DD children would acquire fewer skills;

Second, the skills learned would be less complex than those acquired by nonhandicapped persons;

Third, the number of trials and the amount of time required to reach a functional performance level for a skill are much greater;

Fourth, the DD child tends to forget what he/she has learned;

Fifth, the DD child has problems synthesizing what he has learned to another setting or problem;

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Sixth, the DD person is a poor incidental learner;

Seventh, learned behaviors must be maintained and generalized in real environments if the behaviors are going to be available to the DD person.

Eighth, many developmentally delayed children present medical and perceptual problems which affect both learning and training.

These characteristics demand efficient, effective training of a particular skill to be done in a particular place, by a particular person, in a particular way, over time. I suggest that nonhandicapped children make sense out of their real, home environment and take this knowledge with them to school, or school will be an ineffectual learning environment. Children from poor home environments substantiate this part. Too often the DD child has not interpreted his home environment before he goes to school. Then the DD child will spend years in educational programs, in absentia of real life situations, trying to learn how to function acceptably in a wide variety of heterogeneous non-school environments.

Considering the limitations of the DD learner, we can describe the parameters of developing an individual education program (IEP). The DD child should be trained in skills that have broad use across many situations and problems. The DD child should be trained in his natural environment because of the problem of synthesis, maintenance and generalization of skills. The skills trained should have intrinsic value to the DD child and be selected because they work for him/her. Because of the time and redundancy needed to learn a skill, training should start early in the DD child's life and be done by a person who can do the task time and time again. For these reasons, we have chosen to train DD children via their parents in their natural environments.

One of the specific mandated-related services required by P.L. 94-142 is parent training and counseling. The linkages between the special education classroom and the child's home development can impact on the ability of each setting to enhance the child's development. Fredricks, Baldwin, and Grove (1974) have demonstrated that a systematic program by the parent in conjunction with a school program will almost double the rate of acquisition of a particular skill. However, questionnaires have revealed educators felt the handicapped child's parents did not possess the expertise necessary to actively participate in their child's education. Teachers indicated they thought parents could not effectively plan for or aid in their child's education because some parents functioned too low intellectually, others did not care, and most held unrealistic expectations, or denying their child's problems. Switzer (1985) proposed that if parents were given the information they needed to understand their child's disability, the parent could accept and work with their child's problems. Fulmer, Cohen and Monaco (1985) determined the person inform-

ing the handicapped child's parents of the child's problems must "fit" the information to the particular family's structures and habitual functioning for the family to accept and participate in the child's training. Beckman (1985) found both parents and professionals consistent in their estimations of a child's abilities when given similar strategies for assessing the child. In addition, neither the parent nor the professional over-estimated the child's ability. Witt, Miller, McIntyre and Smith (1984) indicated the parents were satisfied with their child's IEP staffing if they were directly involved in its planning and implementation. Cone, Delawyer and Wolfe (1985) indicated parent income and education were positively correlated to the amount of time a parent worked with a handicapped child in the home. Amerikaner and Omizo (1984) (using the Family Adaptability and Cohesion Evaluation Scales [FACES]) demonstrated that families of learning disabled or emotionally disabled children were significantly more "chaotic" and "disengaged" than families with normal children. But Blacher (1984a, 1984b) noted parents become emotionally organized and adjusted when they channeled their energies into solving the realistic problems of their handicapped child.

For the past 10 years, the Infant and Early Childhood Intervention Program (IECIP) of the Kansas University Affiliated Program (KUAP) at Parsons, Kansas, has dealt solely with the training of rural parents with developmentally delayed children. Information and training has been delivered to the only live-in consistent teacher the child will ever have--the parent--at a cost of $200 per child per year. The parent learned about their child's disability, what and how to train their child in the home and community, and to plan for their child's future. The result has been parents who knew what their child's problems were could work with the child and other similar developmentally disabled children, and could tell you what the child accomplished, learned, and needed to learn to be prepared to live independently.

de Villier's (1979) discussion of the crucial experiences and constraints of language acquisition focused on the importance of the child's parents as his tutors in his natural environment. For years, we have separated handicapped children from their parents and their homes to prepare them to live in "the natural environment." But characteristically, handicapped children find it hard to transfer or generalize an acquired skill from one environment to a different one (Brown, Nisbet, Ford, Sweet, Shiraga, York & Loomis, 1983). Ford and Mirenda (1984) suggested the right number and variety of stimuli in the natural environment covered and confused the relevant cues the handicapped child had been trained to attend to in his structured classroom setting. Donnellan, Mesaros and Anderson (1984-85) recommended that <u>if we are to change the poor outcome for handicapped persons</u>, we must move from the artificial nature of the setting, tasks, materials, teaching formats and curriculum content we now employ and learn to teach them in the natural environment. Halle (1982) demonstrated that if we were to succeed in teaching functional language

to handicapped individuals, we must facilitate generalization to the natural environment where it is actually used.

The quality of the interaction between the infant and his/her caregiver is critical to infant early development (Kelly, 1981). In fact, Rosen-Morris and Sitkel (1981) stated, "The success of an educational program is ultimately tied to the teacher or parent's attitude toward the child." Brooks-Gunn and Lewis (1981) investigated what effects the various temperaments of cerebral palsied, Down syndrome, and mentally retarded infants, ages 3 months to 3 years, had on their parents. These children, like normal children, were individually unique in temperament and tended to change in behavior with change in age and maturity. The parents of these handicapped children tended to physically and verbally interact more with the children if they were less distractible, more persistent in attention, less intense in amplitude and length of response, and less active motorically. However, when maternal interaction was not responded to at the time mothers felt it was developmentally time for their child to respond (due to the child's delay in cognitive and language development), the mothers stopped interacting. As the child fell farther behind the norm, certain behaviors seen as appropriate in young infants, in all likelihood, became aversive to the child's tutor and the child was considered difficult. When parents and teachers of older handicapped children considered the child to be "difficult," they restricted their interaction to commands and directives. In turn, the child did not develop conceptually, and tended to become a greater problem to the adult. The more delayed the child appeared in development in regard to his chronological age, the less the parent interacted.

While nonhandicapped infants and their mothers seem compatible for developing the natural environment into a language training center, the handicapped child presents his/her mother with a distorted cue system that make it hard for her to teach, and them to learn language. Keogh and Reichle (1980) indicated that the handicapped child's environment must be modified if the basic concepts for communication are to be learned. Kelly (1981), Thoman, Becker and Freese (1976), Brooks-Gunn and Lewis (1981), Walker, Levine, and Grasse (1981) suggested the important features of maternal language that foster the development of linguistic skills in normal children are equally, if not more important, to the handicapped child. Research has begun to investigate how a handicapped child's behaviors reduce or eliminate the effectiveness of the child's natural tutor and environment for language. The results are techniques and procedures that allow the child's parents to teach them in their home and community.

The characteristics of children with various handicaps, the coping, interactive, re-adaptation of the mothers, and suggestions for appropriate training techniques were reviewed by Ludlow (1981). Ludlow, (1981), Walker, Levine and Grasse (1981), and Kelly (1981) indicated normal

parents with handicapped children reverted to negative and controlling vocal and nonvocal expressions with their infants and young children, instead of the positive and concept-developing expressions they would use with normal children. Slater (1983) developed a linguistic training program for children of low IQ mothers in deprived conditions which gave these mothers the ability to employ abstract language patterns, emphasize conceptual relationships and encourage their children to solve problems. The program met with significant success. The program developed representative and abstract thinking ability in these children. Interestingly, the language behaviors of the low IQ parents that were replaced by the Slater program were negative, controlling vocal and nonvocal expressions--the expressive modes normal mothers of handicapped infants seem to develop. The program increased the rate of verbal interaction between low IQ mothers and their children. Warren and Warren (1983) found frequency of verbalization to be directly related to the rate of learning and generalization of language skills by handicapped children. Walker et al. (1981) indicated play situations provided more vocal exchange between mothers and handicapped children. In the play situation, the child chose the source of linguistic attention. Research has suggested that the most important feature of maternal language, as related to a baby's acquisition of language, is its referential immediacy and its match with what the baby is attending to and interested in.

In many cases, we have found the child's parent(s) to be the most efficient trainer the child would ever have. Parent involvement greatly accelerated the child's rate of learning. A center, working with a child without benefit of parental involvement, could not begin to accomplish what staff and parents can accomplish together, or the parent accomplished alone with help from parent trainers. Compared to ourselves and other teacher-therapists, the parent could teach across skill areas (eating, dressing, toileting, talking, bathing, etc.), meshing remedial or rehabilitative procedures with basic skills while training the child to perform functionally in a natural environment. Ramsey, Beckman-Bell and Gowen (1980), and Wultz, Myers, Klein, Hall and Waldo (1982) have noted the positive attributes of training in the home. First, unobtrusive tasks were taught in a meaningful rather than artificial way. Second, learned tasks came under the control of natural reinforcers. This contributed to the child's ability to function effectively at home. Third, as the educational activities became part of the daily routine, there was less need to set the child in structured, repetitious sit-down situations to gain a skill. In time, they could teach younger children who do not tolerate the demands of a structured situation. Fourth, and most important, non-obstructive and integrated teaching was done during the daily routine and eliminated the time pressures of formal sessions.

It is surprising to me that we consistently omit the parent as a teacher. We tend to applaud ourselves for a child's accomplishments and direct our scorn toward the parent for a child's problem behavior. I, as you, work

with developmentally delayed children. In many cases, the fact that they exist prior to our intervention speaks well for their parents. We will readily note the inappropriate things a parent does, such as not positioning the cerebral palsy child when feeding, or keeping the child on a bottle past a certain age, or not presenting the child the names of the objects he is manipulating, in allowing him to sit in the W position, etc. We regard this as stupidity when it is actually ignorance on the parents' part. Once told what would be beneficial to their child, you are thanked and the child is the benefactor.

Infant and Early Childhood Intervention Program

Developmentally delayed children create problems from birth for their parents. When the child has complex or numerous medical problems, does not start to walk or talk when he/she is supposed to, has problems eating, etc., the parenting role changes, and parents need help and answers.

Early identification and intervention has been effective in improving the progress and outcome for many DD children. If nothing else, it involves the child with persons who know how to work with the child to help him develop. According to Jorden, Hayden, Karnes and Wood (1977), programs providing early educational and therapeutic programming to meet the needs of young handicapped children and their families are reducing the number of children who will need intensive or long-term help. In turn, these children can often function at higher levels than thought possible in prior years.

Unfortunately, early identification intervention programs are not readily available in rural Kansas. There is not a homogeneous group of DD children. Distance and cost are formidable barriers to program development. Parent groups are hard to establish. Access to the variety of professionals needed to effectively manage and program a DD child is limited. The IECIP is an attempt to address these problems.

Demographics of Southeast Kansas

The economy of rural Southeast Kansas is based on mining, farming and small business. In recent years, the mining business has collapsed and numerous farms and small businesses have failed. Historically, Southeast Kansas never recovered from the great depression of the 1930s. Demographic data acquired from the office of Information Systems and Computing of the Kansas Department of Health and Environment for the years 1980 - 1985, present the following profile of this area of Kansas.

Southeast Kansas has the:

1) Highest unemployment rate in the state (17%);
2) Highest incidence of families below poverty level (11.4%);
3) Highest incidence of individuals below poverty level (15%);
4) Highest incidence of unemployed single parents with dependent children on public assistance;
5) Second highest incidence of families with dependent children on public assistance;
6) Highest incidence of teenage pregnancies (19.4%) compared to 11.7% which was the state's proportion of births of these young mothers;
7) Highest infant mortality rate in the state (9.1%);
8) Highest rate of recorded abortions (41.5%) for pregnant persons under 20 years of age;
9) Lowest index of adequate prenatal and postnatal care;
10) Highest drop-out rate in the state;
11) Highest incidence of illiterate persons;
12) Highest drug abuse rate;
13) Highest incidence of reported abused and neglected children;
14) Highest incidence of reported developmentally delayed children;
15) Highest incidence of premature births.

The problems of Southeast Kansas are compounded by the inability of this area to attract and keep qualified medical or educational professionals. Southeast Kansas has presented health hazards to its populace since the 1930s. Through the 1950s, Southeast Kansas had the highest incidence of tuberculosis and now the highest incidence of cancer in the state. According to National Environmental Agency, Southeast Kansas has the number one environmental health hazard in the nation--Tar Creek. At the same time, Southeast Kansas has the lowest density of qualified physicians, including obstetricians and gynecologists, to deal with those with medical problems.

Southeast Kansas has the largest stationary group of third generation welfare recipients in a four-state area of Missouri, Arkansas, Oklahoma and Kansas. Many of the families fail to promote appropriate prenatal and postnatal care for mother and child, to show responsibility for developing and maintaining a nurturing home environment for the child, and to take advantage of public education opportunities. Children in these homes frequently are delayed developmentally due to environmental as well as genetic and physiological causes. Their mothers receive inadequate prenatal and postnatal care. Most are raised by uneducated parents at home until they go to public school programs or institutionalized. By the time the child enters an educational program, his/her future has already been largely decided. An educational program alone cannot overcome the long-term effects of a family whose primary goal is subsistence.

Parents limited educationally and economically frequently have difficulty nurturing and teaching their disabled children born with intermittent or chronic medical complications. These parents cannot afford needed consistent medical attention. They do not understand the ramifications of a child's diagnosis and that the medical plan is designed to reach a successful and beneficial outcome for the child. Consequently, when their child needs medical help, they frequently do not schedule or keep medical appointments or follow prescribed interventions.

Although the needs of developmentally delayed children begin at birth, in many rural areas intervention programs are nonexistent for such children before age five. Programs providing early programming for young handicapped children and their families can reduce the number of children needing intensive or long-term help. The primary purpose of the Infant and Early Childhood Intervention Program was to develop a model service delivery system for fostering the health and development of young delayed children and unborn at-risk infants in economically deprived rural settings. The system involved infant and child development professionals who improve the overall development of a large number of young developmentally delayed children by traveling to the parents to teach them how to train their children. Procedures were developed to help parents of delayed infants and young children become viable, knowledgeable teachers, case managers and advocates. Such procedures will be disseminated to others serving delayed populations in similar locations.

History of IECIP

The Infant and Early Childhood Intervention Program began as an interprofessional, interagency program between the KUAF and existing service agencies involved with developmentally delayed children and their families, in a sparsely populated, rural area of Southeast Kansas. The program involved the child's physician, county Public Health nurses, social and rehabilitative services social workers, public and independent school personnel, Mental Health Department psychologists and counselors, and the child's parents. Initially, we informed and trained each other in regard to functions and roles. The KUAF educated its sister agencies regarding the need to provide developmentally delayed children appropriate medical and educational procedures and therapies as soon after birth as possible.

At first, KUAF staff were primarily interested in initiating procedures for identifying developmentally delayed or at-risk infants at birth; however, other agencies expressed their concern with the needs of developmentally delayed children in their communities who were not receiving help. At that time (approximately 10 years go) in our region of the state, parents of even identifiable DD children (such as Downs syndrome) were not informed of their child's problem until he/she was

two- to three-years old. Then, the child was directed to a state institution. Thus there was a need to provide services for children regardless of age.

A transdisciplinary training and service model was first attempted. The main persons actually involved in the transdisciplinary training are the child's parents.

Basic premises: Their are some 19 basic premises of the IHCIP. These are as follows:

1) When parents think there is something wrong with his/her child, we will work with them to discover if there is a problem.

2) Our purpose is not to diagnose or name the child's condition; we want to determine where the child is developmentally, identify and eliminate factors impeding the child's ability to develop, learn how to best teach the child, and take the child forward developmentally--we do not concern the parent with where the child should be.

3) It is important to initiate remediation on a developmental problem as early in a child's life as possible.

4) The child's parents are the authority on their child, and they are our peers; it is their responsibility to raise their child, not ours--we work with each other.

5) The child's parents, their attitudes, and the environment have the long-term overriding effect on the child's development and eventual outcome. You cannot change the child unless you change their parents and their environment, too!

6) Parents do many things right for a special child without intervention.

7) Parents are capable of training DD children in most areas of learning with direction and information from other experienced professionals.

8) For continuity in long-term learning, for continuity of programming, for intensive training, for maintenance and generalization of learned skills, and for an affordable program, we believe the child's parents must become the teacher of their DD child.

9) We never tell the parents we will teach their child; we do train the parents what and how to teach their own child.

10) DD children have problems synthesizing the separate skills they are taught for effective application.

11) The most important need of a special child is environmental adaptation--to train the child to exist and function in his home environment (home, grocery stores, restaurants, movie theaters, churches, etc.). Next comes reading, writing and arithmetic.

12) The child's rate of progress determines our objectives and goals; diagnoses and prognosis are kept tentative.

13) The child's improvement is based on time; the amount of time spent in one-on-one training experiences at the child's learning level is a crucial factor in determining the child's progress.

14) We are involved with the child for a long term; consequently, we emphasize continuity in programming.

15) Learning should take place where it can be maintained and generalized.

16) Programs which take the DD child away from the places and persons instrumental in the child's development are at best ineffective and at worst destructive; such programs attempt to serve the DD child under the guise that professionals can do it better than the parents and with the child being taught in situations limited in time and opportunities and separated from the natural environment--in some cases the parent is not even told what the child is being taught and parents are seldom involved in the training.

17) We disagree with the segregation of most DD children by their parents and educational systems from their environment and experiences with "normal" children. The appropriate model for a DD child is a normal child. In turn, this is a good time for normal children to learn to understand and accept DD children.

18) In many special education systems, the DD child is taught how to succeed in school but not in his home environment or community. The parent is the child's main teacher of how to live outside an institution.

19) Our goal is to make the DD child a future functional independent, self-supporting adult.

Elements of the Program (Hedge, 1987)

1) We have a cost-efficient method to train developmentally delayed children. One parent-trainer can work with 150-200 individual parents and their developmentally delayed children.

Where: At home in the developmentally delayed child's natural environment.

What: Selected skills they are ready to learn which they will use and need for living.

When: Early in life to prevent the breakdown of the parent-child relationship, to afford time and redundancy for learning; before the child looks out of place; before unacceptable attitudes and behaviors intervene.

Who: The parent, family, people in the child's own community (we learn about each other from being with each other).

2) We don't send the developmentally delayed child to a program--we send them home to their mothers.

3) We teach parents what to teach or train their developmentally delayed child in a developmental sequence, in the areas of communication, gross-fine, perceptual motor development, social and behavioral adjustment, self-help, and cognitive skills.

Weatherford (1986) indicated many parents have the desire and willingness to help their children, but lack the knowledge and skills to do so. Well designed programs will address this parental need.

4) We train the natural parents, other family members, foster parents, adoptive parents, guardians, friends of the child and family, baby-sitters, teachers, and other persons involved with the child (doctors, social workers, public health nurses, mental health workers, teachers, etc.).

5) We usually train the mother as the developmentally disabled child trainer, case manager and advocate. Mothers seem to look at their developmentally disabled child differently than do fathers--the father often seems embarrassed and, at first, tends to disown their DD child. We attempt to work with the father, when and where possible, but are happy if the father will support the mother in her efforts to train their child.

6) Services to the client and parent cross many adaptive goals. We teach some parents to maintain the child's existence and overcome or remediate physical problems. Our main goal is to help the parent and child adapt (as much as possible) to home and community existence. Others we prepare for community living, degrees of school learning, and levels of functional, independent living in their community.

7) We facilitate positive interaction between the developmentally delayed child and his parents. While there naturally exists, in most cases, the evidence of what we call bonding between a newborn and the mother, the numerous problems associated with the developmentally delayed child

usually result in an estranged if not a detrimental relationship (Blacher, 1984; Hanson, 1983; Kelly, 1979). The parents care is shortly reduced to a custodial rather than a nurturing experience for the child. We draw attention to the child's abilities and the progress of the child, which often comes in small increments. We tell what these steps mean to the child's development.

8) We intercede between the parent and child to prevent the establishment or continuation of attitudes and behaviors that will slow down or stop the child's progress. The earlier these are recognized and eliminated in the child-parent relationship, the more effective the developmental program.

Some attitudes and behaviors detrimental to the parent-child training relationship are:

(1) Feeling sorry for the DD child or themselves
(2) Guilt
(3) Embarrassment
(4) Fault finding--blame anyone but---
(5) The switch theory: "He'll grow out of it, one day he'll be OK."
(6) Hopelessness--helplessness
(7) The never ending search for cause and cure
(8) Stress

Snell and Beckman-Brindley (1984) indicated that the stress of a developmentally delayed child may be due to a variety of reasons:

(1) Worry about child's day-to-day survival
(2) Guilt and anger about child's future
(3) Reduction in leisure time, social interactions, sleep
(4) Extra expenses--education, medical, equipment, therapy, family income reduced--one parent works, other at home
(5) Funding for medical, education, respite, dental care

9) We help parents find funding for what the DD child needs.

10) We help parents cope with stress. Early intervention seems to give needed support and direction to a child's family. You bring a lot of answers for questions not ever asked or presently needing solutions. We see less guilt, worry, anger, depression. The parent gains direction, can do something about their child's problems, and see progress.

11) We often start with the parents early enough to prevent the formation of detrimental habits between the parent and child, e.g., aberrant behaviors, withdrawal, misinterpreted communications, self-injurious behaviors, and/or inappropriate social behaviors.

12) We do not usurp the mother and father's responsibility for the training of their DD child by directing the child to someone else. In our program, we are there to work with the parent, the parent is there to work with the child.

13) We do not consider the DD child as "our child." He/she is always the parent's child. We have noted that many teachers or therapists who work with a DD child individually, refer to the child as "their child." This seems to signify that the teacher or therapist solely considers him/herself the main resource for the child's developmental needs, and has disinvolved the parent from their child's training.

14) We direct parents to persons with programs for their child only if the person can help the parent with the child's needs. Karnes and Badger (1969) identified the problem in maintaining parent involvement when the child is placed in a preschool program. We have the same problem with our parents who place their DD child in a developmental preschool. Karnes and Badger found the intervention in the home involving mothers of disadvantaged children resulted in a 16-point higher performance in IQ for the experimental group children versus the comparison group.

The addition of a preschool program to augment these children's development had a negative result. After two years in the preschool program, with the reduction of parent involvement, their was no large difference between the control and experimental groups IQ.

The crucial change cited in the program was considered to be the inclusion of the preschool program. This combined with the reduction in the number of at-home visits may have led to the mother's belief that they no longer played a crucial role with filling the development of their children.

15) We help parents find doctors, dentists, ophthalmologists, geneticists, evaluational programs, teachers, etc., who will take the time to explain, discuss, find a way to tell the parent what their child's problems are and what to do about them. We direct parents away from professionals who deal ineffectively or do not want to work with developmentally delayed children.

16) We connect parents of DD children with other parents of DD children who can help them solve their problems.

17) We facilitate community understanding and acceptance which benefits the child. Most children and adults will accept and help the DD child grow into adulthood if they know why they are the way the are, know why they act the way they act, and most importantly, know what to do and how to help. We cannot put the DD child in a family, institution, or school "closet" and expect the child or the people in the child's community to

suddenly understand or accept the DD child or adult when he/she suddenly appears. The DD child and his community must grow up together.

18) We work with the parents for long periods of time, until they can deal with their child without us. For this reason, we do what is necessary to develop and foster a long-term relationship. Harris, Walchek and Weitz (1981) observed that gains made by autistic children were lost when parent training stopped. The authors suggested the loss of information, direction and support by the consultants to the parents was the reason for program washout.

19) We develop a one-to-one training program between the parents and their DD child. Schearer and Schearer (1975) acknowledge the benefit of the home-teacher working on a one-to-one basis with the parent and child; the results were that individualization of instructional goals became an operational reality.

20) We do not tell the parent how many times to do an exercise or task. We do describe what we want to attain before the next training meeting.

21) The parent trainer usually selects the tasks, techniques, procedures, materials and situations the parents will use to train their DD child. The parent trainer trains the parent. The parent trains the DD child.

22) We are available to work with the parent(s) any time during the day. We schedule time with the parent and child which they can consistently meet that is not detrimental to their life-style. We are available by phone or in person, if problems arise between scheduled meetings.

23) You must be dependable and consistent if you are to become an effective parent trainer. I feel the parents, in part, determine the importance and necessity of working with their DD child from the parent-trainer's behavior. You give meaning, importance and value to what the parent is doing.

24) You show the parents your level of commitment by following up in person or by phone--areas such as parent confusion, fears and concerns, the DD child's illnesses, medication, problem behavior, relapses, failures, family problems, scheduling problems, etc. You do what you say you are going to do, thus showing the parents that they and their child are important to you.

25) We collect data only if needed to prove the training is effective or ineffective. If growth is visible, we don't encumber the parents and ourselves with data collection. We will use data to prove a parent attitude or behavior is negatively effecting their child.

26) We make or select training material and environments from the DD child's natural milieu to be used for training. We also introduce needed materials. When the parent makes materials for their child, they are used more and last longer. In turn, the child knows we took the time and effort to make things for him/her.

27) The materials are designed to meet the present individualized need of the child.

28) Any formal testing is done over time and after we feel we know the child well enough to know if he/she is performing for us. Even then, we consider the results tentative--merely descriptors of that particular child at that particular time. We initially learn more by observing how the DD child interacts, controls or manages others, and manipulates objects in his environment. From our initial session, we have the parent describe, evaluate, record, and interpret what their child is presently doing. Grossly, there is limited normative data for the developmental sequences of DD children--in turn, few if any, real ways to evaluate or test.

29) We involve the parent in describing, evaluating, recording and interpreting for their child. They, in turn, give the parent-trainer an enormous amount of information which is used to train the individual parent and the DD child. How the parent(s) do the evaluation tasks tells the trainer how well the parent(s) will approach the training tasks.

30) Our goal is not, simply, change the child's IQ. In fact, we do not attempt to determine the child's IQ. IQ has nothing to do with placement in our program, as it does with other programs. We look at the child as a developing achiever or learner, moving or growing toward self-actualization, based on his/her natural ability and the efforts and efficiency we and his parents have as his teacher(s). Behavioral and sensory problems prevent adequate testing and test interpretation for most of our clients.

31) We deal with where the child currently is, not where he or she should be developmentally, and work to achieve the <u>next</u> level of development.

32) We train the parents how to maintain and generalize skills they have taught their DD child in the natural environment. However, separate tasks needed to maintain and generalize a certain skill are seldom necessary, since we train the skills the child will need and use in the natural environment where they come under the control of environmental reinforcement. Whitman, Hurley, Johnson and Christian (1978) found that when we use school-like fabricated learning tasks and situations which are not part of the DD child's daily routine, long-term learning is improbable.

33) An important element, to be considered, is time. We have suggested a DD child required more trials, and meeting time to learn skills. We train the DD child's parents to evaluate progress by the amount of one-on-one time they spend training their child. In all training situations available to the DD children in Southeast Kansas, none have the time to train him/her as effectively, efficiently and economically as the child's parents (Hedge, 1988). Hedge maintained the parent-training model affords the needed time, at an affordable cost, to present the required number of trials so a DD child can learn a skill. The parent is not limited by the time/length of the session. The parent can work as long as it takes to achieve a stated objective or goal with natural time restraints of their life style. The time of training occurs in the place where the skill is needed, will be used at the end and can be maintained and generalized under natural contexts and reinforcement. The skill will be trained time over time in the natural environment. The time of training the skill is appropriate for learning when places are open or closed.

34) We help the parents interpret, understand and adjust to the variety of test results, diagnoses, prescriptions, program placements, programs, prophecies and professional demeanors.

35) We train the parent to know what their child has achieved developmentally, what evaluational and educational systems use to describe and prescribe for their child, and how and what the parent needs to inform the system about their child to positively affect program development.

36) We train parents how to push professionals and programs for needed services for their DD child.

37) We work with the parents of DD children with a variety of handicapping or combination of limiting conditions and situations. Included are children from deprived environments, battered and abused children, mildly to severely handicapped children.

38) We provide needed professional services not available--orthopedic, cardiology, audiology.

39) We provide respite.

40) We train parents based on their ability, competency, interests, willingness, environment, situation, and most importantly the time they have to work with their child (Hedge, 1988). Some parents do not choose to work with their children. Our ability to fit a parent training program to each individualized parent has resulted in most of the parents we have contacted becoming effective trainers for their children. Over time, parents tend to become more effective trainers, to habituate to training their child, and training seems to interfere less with their lifestyle.

41) By now it is obvious that few parents will be the constant, consistent, always-motivated child trainer you might expect them to be. They are just like you. Some days they just don't feel like going to work. You must be realistic and expect and accept this behavior, and not make the parents feel guilty if their child shows regression. The child needs a break, too.

42) Families referred to you or who contact you may not be ready or able, at that time, to become parent trainers. In most cases you will find yourself valuable to them in other ways. Refer the parents and child to other professionals who can alleviate problems the parent/child have which require time and attention. Provide appropriate information to the parents regarding their DD child. Arrange situations for the child and family to aid their adjustment to each other. You find some reasonable approach to keep in contact with the parents until parent training is appropriate.

43) The amount of parent training varies according to parent ability to meet their family's needs and work with their DD child. Hedge (1988) has indicated that once you have learned to effectively work with the parents of a DD child, you begin to recognize your limitations in training their child in contrast to the parents' advantages. You recognize the parent succeeded where you failed, the parent finished what you are still working on, the parent can work on more tasks at a time than you, and the parent does not need to be concerned with "carry-over." In the twenty years I have worked as a parent trainer, I have developed some attitudes and ideas about what I think works (Hedge, 1987). Some of these are below.

What and How to Train Parents

a) You must select tasks the parent can do with the child that show results.

b) You attempt to teach the parent what their child's particular combination of learning and physical problems and abilities mean to their child's way of developing; and create tasks, objectives, goals, procedures, techniques, materials, and situations from which the child can be taught by his parents in his natural environment.

c) You teach different parents different ways. Some parents need a lot of direction, explanation, motivation, structure, time limits, reinforcement, support, attention, time, redundancy. Cheseldine and McConkey (1979) taught "natural" language training procedures to the parents of preschool Down syndrome children. They found some parents functioned effectively with little instruction while others performed the needed task effectively only after specific step-by-step direction.

d) You observe individual parent approaches and attitudes toward their children. You adapt your training to the particular parents' style, or change the parents' style if it's considered detrimental.

e) You work on ways to motivate parents to work with their child and discover the key reinforcers for the parents.

f) You talk to each parent differently at different times. You scold some; you only reward others; you demand, direct, ask, request, offer choices, explain why, etc.

g) You find yourself in a variety of changing roles each day. You raise the parent as your child if they need that type of relationship. You are a colleague, if that type of relationship is required. You are the child's authority, if they want/need leadership. You become an authority figure if the parent needs someone to tell them what to do. In almost all cases, you and the parent become friends, someone you talk to about your life, your children, your problems. You develop sincere, open, cooperative relationships with each parent--a partnership.

h) You do not work with the child alone. You train the parent to work with their child. You teach the parent how to look, listen, think about, accept.

i) Most parents do not have preconceived ideas of what their DD child will or will not be able to do--a self-fulfilling prophecy.

j) You do not form first impressions. We have found one cannot determine how well a parent will be able to train his/her child by what he/she looks like, talks like, or acts like. One cannot determine the amount of stimulation in the home by how clean, cluttered, structured, or dirty it might be. The existence of stimulus materials in the home does not indicate use.

k) You believe all children can learn--if we can teach them. We do not believe some children can learn while others cannot.

l) You use your experience as a teacher or therapist to draw the parents' attention to unrecognized abilities and gains in the child's development.

m) You deal with how the parents now trains his/her child, how the child has trained the parents, and how you can train the parents to train the child.

n) If you are going to be able to help the parents teach their child to talk and walk, you must be able to teach the parents how to foster appropriate learning behaviors.

o) To train parents, you must be able to explain the same concept as many ways as there are parents who need to work with the concept.

p) Positive change in the development of the DD child is the result of the parents' work with their child.

q) If a child is not growing or developing, it's your fault. We are likely teaching at a level too high for him/her. You do not blame parents. It's up to you to affect change in parents, which in turn affects change in the child.

r) Do not take away the clients' or parents' dignity.

s) Treat the parent as a colleague. Constantly keep in mind that the child's primary and continuing educational relationship is with his mother (parents).

t) There are certain issues we leave alone--you better know these!

u) Don't push parents into what they are not ready to accept, such as the gravity of the child's condition so they can be "realistic in their expectations." We feel this comes with time. If you push, it's because you don't give time or have time to deal effectively with the parents of a DD child.

v) You often work to draw the parents' attention to the similarities in behavior of the DD child and nonhandicapped children. Parents of DD children often overlook the child when concerned with the problems.

w) It's appropriate to talk about other things in the parents' lives besides the child.

x) You do not tell a parent of a DD child you know what they are going through--you don't.

y) You must be able to compromise.

Description of IECIP Services

The IECIP is an interdisciplinary and transdisciplinary approach serving the developmentally disabled population, primarily ages 0 to 6 years. The IECIP provides services in the areas of gross and fine perceptual-motor development, speech and language development, socialization, behavior management, self-help, environmental adaptation, and evaluation. The IECIP is available to the Southeast Kansas population at no charge. The IECIP is funded by the University of Kansas/Bureau of Child Research

core grant and matching federal/state funds. The administrative cost of the program is approximately $200 per client, per year. This cost plus low travel to centrally located provision points for families makes the IECIP's parent training approach feasible and financially possible.

The total population served by the IECIP is approximately 350 DD children and their families. Diagnosis for some of the children involved in the IECIP are autism, cerebral palsy, Downs Syndrome, microcephalus, hydrocephalus, Russell Syndrome, Williams Syndrome, Pierre Robin syndrome, as well as other known and unknown forms of developmental delay. The characteristics of the environment and population of children we work with in Southeast Kansas predispose them to environmental neglect and delay. The program covers a region of 15 Southeast Kansas counties. There are 18 provision points (not counting home visits) in specific cities in the region where weekly or bimonthly contacts are made with the child and their parents. The program is held in the offices of county public health, mental health, social and rehabilitation agencies, hospitals, city halls, public/private schools and some homes.

The IECIP team travels into the catchment areas to the designated provision points to serve the individual child. In addition, when the child is ill, extremely young, or there are transportation problems, the IECIP staff provide services in their homes. This tends to alleviate the expense of travel that hinders center-based programs with lower socioeconomic persons. Many low-income parents cannot afford travel or do not have transportation.

The IECIP model involves the development of parent competencies in implementation and evaluation of developmentally/behaviorally based intervention programs. Based on the principles of individualized programming, the trainer and parent develop the goals, techniques and materials for the child. The program is geared to the age of the child, chronologically, physically and emotionally. If a client is an infant, the program emphasizes motor, communication, and cognitive development. If the client is older, the program directs itself toward self-help, communication, sensorimotor integration, the interpretation of the environment, preparedness to become an adult, and school readiness. The program also directs its efforts toward aiding parents in handling the inappropriate disruptive behaviors of their children.

Services delivered are specific to the client's needs and disabilities. The gross/fine perceptual-motor component breaks the specific needs into two areas of contact--motor development and sensorimotor integration. Direct application of remediation is dependent under which level the client is functioning. The speech and language component encompasses the levels of pre-speech and receptive and expressive language, pre-academic readiness, and behavior management. The psychological component provides complete cognitive and adaptive behavior testing and instruction in

behavioral management techniques for handling inappropriate and disruptive behaviors. The social work component offers parental counseling, behavior management techniques, respite care programs, and home-based intervention in crisis situations. The IECIP thus offers an interdisciplinary approach to the rural-base environment through four components.

Interactions between the IECIP staff, the child's physician, public health nurse and social worker extends the care of the DD child to involve his hygienic, medical, and welfare needs. Approximately 40% of the DD children referred to the IECIP come from the child's physician, public health offices, public schools or the social welfare systems. The majority of our referrals are via the parents of DD children we are presently working with or have helped in the past.

Following referral, the child is placed on the waiting list for his/her catchment area, or entered in the program at a time and place where the IECIP staff, the child and the child's parent(s) can consistently get together. The initial contact with the child and parent may last minutes to hours and the child's needs may be observed and evaluated by one or all the IECIP staff members with the help and input of the child's parents and other family members. The staff members' abilities to involve the child's parent(s) in the description of the his/her problems and needs is considered an important element in training them as the child's teacher. The parent leaves the initial meeting with an assignment involving the recording of observable behaviors important to determining the child's present level of motor development, communication, cognition, socialization, or the child's aberrant, counter-productive activities considered in conflict with the child's growth and development, as well as a few specific training goals and techniques to use daily with the child.

The above system involves the parent(s) immediately in the description of their child's developmental problems and procedures they can do to improve their child's development. The staff member must meet three criteria when he makes an assignment. One, the assignment must offer observable improvement in the child's development; two, the assignment must be something the parent can do; and three--and most importantly--the assignment must be something the child can do. These three criteria result in a feasible, practical and workable program for the child.

After the initial meeting, trainers, parent(s), and child meet weekly or bi-weekly. To achieve program criterion, each meeting with the child and parent involves essentially the following format. The child, parent and staff member discuss and evaluate together the success or failure of the last assignment. The staff member asks the child's parents about their experiences with the past assignment, often having the parent demonstrate the procedures they have consistently performed with their child. This procedure tells the staff member if the parent has been doing the assign-

ment and how the parent has been doing the assignment.

Young children often perform better with their parents working with them, thus allowing the staff member to observe where the child is, as well as what problems the parent(s) is having working with their child. The staff member tells the parent what the parent has accomplished with the child. The parent and the staff member then work with the child to determine whether to continue the present assignment, change the assignment, because the procedure is not working or move to the next level of training. The staff member discusses the purpose of the next assignment, models and explains the criteria for successfully performing the procedure, and practices the procedure with the parent working with the child until both know what will be happening to the child until the next meeting.

To insure understanding and application of the assignments, the staff member is on call to the parent by phone or in person. Before the parents leave the meeting, they are given a written description of the assignment, as well as any materials they will need, (not available in the home) for doing the assignment. Often materials are made by the parent and staff member for the child. We have found parents and their child use more consistently and take better care of materials they help make. The parent tends to become self sufficient in meeting the needs of the child and less dependent on others.

Contact between the staff member, child and parent is intense, with particular emphasis on educating the parent on the specific problems of their child, defined over time by the IECIP staff and the child's parents. The parent is the focal point of therapy with the particular child. They determine what, how, and how much will be done. Grossly, we find parents able to consistently achieve more over a long period of time with their child than any other present system.

The home and community environment becomes the child's therapy room. The parents become the child's developmental specialists--teacher, case manager and advocate. By working with parents, the IECIP staff is able to affect many more children than they could working individually with a child, thus increasing the number of children helped in the catchment without a concomitant increase in numbers of hired professionals. Each of the IECIP staff members is impressed with the greater growth in child development (over time) with the parent being the trainer than was ever expected when working with individual children in private, public or university therapy programs.

Support Programs for DD Children

KUAF at Parsons personnel have developed cooperative services for DD children and their families with Kansas Crippled Children (KCC) and

Parsons State Hospital and Training Center (PSHTC). The KUAF and KCC provide a bi-monthly orthopaedic clinic involving orthopaedic surgeons, nutritionists, prosthetic specialists, physical therapists and social workers. The KCC program also provide genetic counseling and pediatric cardiology.

Over the ten years the IECIP has been in existence, the staff of the program, with the first-hand help of the parents of DD children, have developed a listing of professionals in the area who are willing and capable of treating children with special problems. This list includes dentists, orthodontists, pediatricians, pediatric allergists, optometrists, otorhinolaryngologists and audiologists. The appropriate management as well as the diagnosis and treatment of the recurrent and special medical problems of DD children is a major factor affecting child development.

Respite Care Program

In addition to the services provided by the IECIP, the UAF's Respite Care Program offers another set of important services to parents of handicapped children in Southeastern Kansas. The purpose of the KUAF Respite Care Program is to provide those persons responsible for the care of developmentally disabled individuals with intermittent, brief periods of relief or time off from the heavy demands and constant stress of caring for their disabled child or adult. Respite care offers not only relief to the family, it provides for growth, development and normalizing experiences for the disabled individual through interaction with others in the community. It is the intent of the respite service program to reduce the need for institutional or other out-of-home placements, while strengthening the coping abilities of families and improving the quality of family life.

Comparison to Other Programs

In previous conference presentations when we have described our program as a home-based parent-directed program, we have encountered comments from other professionals that their programs are also home based and stress parent involvement. However, in subsequent discussions with these individuals, we came to realize that their programs differed from ours along a number of significant dimensions. In the paragraphs below, we will attempt to further clarify what we believe are the important parameters of the IECIP. Further, we will compare our program with several others, based on published descriptions of those programs.

Personnel

In recent years the IECIP has employed a speech therapist, a motor development specialist, and a behavioral psychologist. In the past, other professionals have participated on a limited basis including an audiologist and a feeding specialist.

Other home-based or parent-as-trainer intervention programs have also involved: nurses (Dunst, 1985; Hardy-Brown, Miller, Dean, Carrasco, & Thompson, 1987); paraprofessionals (Gordon, Guinagh, & Jester, 1977; Shearer & Shearer, 1972); special education teachers (Dunst, 1985; Shearer & Shearer, 1972); social workers (Dunst, 1985; Hardy-Brown, et al., 1987); pediatricians (Dunst, 1985); physical and occupational therapists (Dunst, 1985).

Services Offered

In recent years the IECIP has provided services to parents in the following areas: speech therapy, behavior management, motor development, other developmental stimulation (e.g., self-help, pre-academic, etc.), feeding problems. Although these are the areas generally targeted for child progress, staff frequently provide other services on an as-needed basis. These service are of a family support nature and involve such things as helping parents: find solutions to children's medical problems; advocate for their children in regard to public school program placement, IEP goals, curriculum; etc.

While these service areas are similar to those addressed by other programs, there also have been descriptions of programs providing individual and family therapy in the home (Hinckley & Ellis, 1985; Hardy-Brown, et al., 1987).

Service Delivery Sites

Depending on the families' transportation resources, the children's problems, etc., IECIP staff may provide services in the home or at one of 18 regional sites (welfare offices, public health offices, city/ county buildings, churches, etc.) near the home. The cost of the program is greatly affected by conducting the training in SRS offices, city halls, public health offices, and other (no-cost) public facilities. Our service is in conjunction with the services provided by the professionals existing in the communities where we see clients. This contrasts with other programs which generally are either exclusively center-based (e.g., Bricker & Dow, 1980; Rosen-Morris & Sitkei, 1981; Safford, Gregg, Schneider & Sewell, 1976) or exclusively home-based (e.g., Cochran & Loftin, 1980; Hardy-Brown, et al., 1987; Perkins & Walter, 1987; Shearer & Shearer, 1972).

Who is Accepted for Services

Children are referred to the IECIP for a variety of problems including behavior and emotional problems at home or school, speech delays, and learning problems. It generally has been the policy of the IECIP to say "Yes" to the referral source when asked if we would see a child. We feel that this approach is one of the characteristics of the IECIP program that provides good relationships with our referral sources.

Once we have met with the children and their parents, if it appears that IECIP staff do not have the expertise to address the child's problem, then we work along with the parent to find someone who can be of assistance. For example, we may make several phone calls to find a physician or therapist who seems to have a special interest in the presenting problem. We consider it extremely important to refer the parent and child to a person we know can and will meet their particular needs. After a child and the parents are referred to another professional, the IECIP staff try to contact the parents to find out if they were helped and if they were satisfied with the services.

In instances when IECIP staff initially did not have the expertise to provide the needed services and the appropriate services could not be located within a reasonable distance, then IECIP staff have made an effort to gain the skills necessary to help the family.

We are not aware of other programs descriptions that have addressed this aspect of intervention.

Cost Per Client

Annual costs to provide IECIP services have been calculated at approximately $200 per client (Hedge & Johnson, 1987). A description of a similar parent-as-teacher program lists costs at $622 per year per child (Shearer & Shearer, 1974). We are not aware of the costs of center-based programs, but would anticipate them to be much higher.

Maximum Years Child Can Be Served

Although services for many children are terminated when the initial referral problem has been solved, those children with mental retardation or other chronic delays (e.g., autism) may continue to receive IECIP services indefinitely. For example, three of our present clients have been involved in our program for 12, 15, 16, years, respectively. Many other programs, it is assumed, terminate services when the child reaches school age (5 or 6 yrs.).

Transdisciplinary/Interdisciplinary

While each IECIP staff member has a primary professional identity (e.g., Speech Therapy, Psychology, Motor Development), there is an element of "the country doctor" in our activities. In other words, the small IECIP staff and the limited availability of resources in this geographical area has resulted in the professionals learning to provide services outside the field in which they were originally trained. In addition, consultations and direct help are frequently sought from professionals in other agencies, such as welfare and public health departments. This has resulted in a combined transdisciplinary and interdisciplinary approach.

For example, if the psychologist is working with a child that displays speech problems and nutrition problems, he will consult with the public health nurse for that region and will try to arrange for the speech therapist to work with the family. However, if the speech therapist has a scheduling conflict, the psychologist will address the speech problems himself (with consultations with the speech therapist as needed).

Although some program descriptions mention transdisciplinary approaches (e.g., Dunst, 1985), the exact nature of such services generally has not been clearly described. In other words, we have been unable to determine from published program descriptions whether single professionals in other home-based and parent-as-trainer programs provide parent training or other services across two or more disciplines. Shearer and Shearer (1974) do describe the reliance of professionals in other community agencies to supplement the limited staff in their program.

Frequency of Visits/Sessions

The IECIP schedule typically allows for one visit bi-weekly. Clients living in our home area have been seen weekly. In addition, more visits are arranged when it appears that two weeks will be too long between visits. It also has been possible to use telephone calls to bridge the time between visits. (Earlier attempts to limit visits to once monthly were found to be problematical.) Other programs reportedly have involved visiting: twice weekly (Gordon, Guinagh & Jester, 1977); weekly (Shearer, 1975); and monthly (Perkins & Walter, 1987).

Length of Visits/Sessions

IECIP sessions vary in average length from 15 minutes to 1 hour. Speech therapy and educational training sessions involving the speech therapist are generally scheduled for 15 minutes. Behavior management sessions involving the psychologist currently are scheduled for 30-45 minutes. Sessions for gross-, fine- and perceptual-motor development last 30 to 45 minutes. When necessary, for example during initial visits and sessions

in which the child tantrums, a session is extended. The length of sessions in other home-based or parent-as-trainer programs typically has not been reported. One exception is the Portage Project which schedules visits of 1.5 hours (Shearer & Shearer, 1974). Sessions are goal-oriented. We work to achieve a level of parent-training/parent-understanding and their ability to demonstrate the task(s) that result in the prescribed training change for the child in the next one or two weeks.

Percentage of Teaching/Training/Therapy Done by Parents

IECIP staff do not provide direct services to the child. Interactions with the child are done to assess progress and to model procedures for the parent(s). While there appear to be other programs that involve parents as the child's teacher/therapist (e.g., Shearer, 1975; Perkins & Walter, 1987; Gordon et al, 1977), this approach differs from most center-based models in which the main instruction/ therapy is provided by the staff, with parents primarily used for generalization and maintenance.

Who is present during visits/sessions

Because IECIP staff do not provide direct services, the child and at least one caretaker must be present with the child during each session. Whether the referral involves inappropriate displays of behavior, speech, or learning difficulties, the problem is viewed as belonging to the family--not just the child. Therefore, the problems and possible solutions are discussed with both caretakers and children present.

Other home-based or parent-as-trainer programs seem to be take similar approaches. For example, Hinckley and Ellis (1985) describe a mental health program in which therapy is provided in the home with the involvement of at least one caretaker and as many other family members as possible. Likewise, Portage Project staff require the parent to stay with the staff member and child throughout the session (Shearer & Shearer, 1972).

Degree of Structure

To date, IECIP staff have tried to minimize the number of formal case conferences, amount of time involved with paper work, etc. Because we are not a public school program we have not had to provide written IEPs or formal transdisciplinary staffings on each client. Nor have we had to conduct lengthy formal evaluations. Because we are not a research program, we have not used complex data collection systems.

Generally, we utilize developmental scales and our knowledge of developmental progression, reports of other professionals (e.g., public health nurses, welfare workers), parents' verbal reports, parents' notes,

parents' collected data, and brief observations of the child to assess his/her child's status and progress. Our goals are informally worded and of short duration; i.e., we try to set goals that can be achieved by our next visit. In regard to assignments, we encourage the parents to be teachers/therapist throughout the day. We seldom specify the number or length of times the parents should work with the children. Rather, we encourage them to spend as much time on the suggested activities as possible. Consultation with other professionals is on an as-needed, rather than scheduled, basis and generally involves informal discussions with one or two other professionals involved in the case.

Other programs appear to involve more standardized procedures. For example, one description of the Portage Model notes that all children are administered the Alpern-Boll Developmental Profile to assess functioning level during each developmental level, then they use of the Portage Guide to Early Education to facilitate planning (Shearer & Snider, 1978).

Functional Materials, Locations, and Skills

As recommended by Lewis (1987), the IECIP places a heavy emphasis on the use of functional materials to train functional skills in functional locations. In other words parents are trained to teach their children skills that will be beneficial in coping in the real world rather than in an academic environment. For example, receptive language may be taught in the kitchen while getting out utensils to set the table; the value of coins is taught in the grocery when buying a loaf of bread or pieces of candy.

We presently are aware of only one other home-based or parent-as-trainer program that emphasizes this functional approach--the Portage Project. Their descriptions also stress the importance of functional curriculum goals, implemented in the natural environment, by the family, using materials found in the home (Shearer & Shearer, 1974, 1978).

Consistency

We believe that one of the keys to our program's success is the consistency of our appointments. Families learn that their appointments are every two weeks and that cancellations and rescheduling are extremely rare. It is estimated that out of each family's scheduled 26 bi-weekly visits, therapist cancellations amount to less than 5 (due to illness, vacations, conference attendance, etc.). We were unable to determine how other programs compared on this variable.

Staff Aggressiveness

In regard to cancellations, "no shows," and clients terminating services prematurely, IECIP staff make a concerted effort to contact each family in such situations. We try to determine what the problem may have been, express our regret at the situation, and encourage the family to return at their next scheduled time. It is not unusual to attempt to reschedule the missed appointment within the next few days. Again, we were unable to find reports of this variable in descriptions of other programs.

Nonproductive/Uncooperative Parents

Because of the important advantages of home-based, parent-directed interventions (Hedge & Johnson, 1987; Shearer & Shearer, 1974), IECIP staff are extremely persistent in their efforts to encourage parents to work with their children. Accompanying this is an attitude that even parents from illiterate families, the lowest SES levels, from single-parent families, etc., can be viable teachers for their children. To some extent, individual assignments are tailored to the family situation. However, IECIP staff use a number of techniques to persuade and encourage parents. This ranges from social reinforcement in the form of using modeling and verbal instructions instead of written assignments or providing praise and excitement for progress obtained, to verbal scoldings or eliciting help in the form of pressure from welfare agencies and courts. It is extremely rare for an IECIP staff member to "throw in the towel" and admit that a parent cannot be encouraged to do the job.

Most other descriptions of home-based and parent-as-trainer programs have not mentioned these issues. However, Shearer (1975) does describe similar efforts to elicit parent cooperation and participation, within the Portage Project.

Position Statement

We have worked to change from an agency-parent with DD child relationship to a parent-trainer/parent-of-DD-child partnership.

If you accept the importance of maintaining the parent-DD child relationship and providing the parent of a DD child with the information, support and training, to accept understand, train and plan for their child, you ask, "what do you do and what do you see other professionals or programs doing to meet this goal?"

Our observations of both private and public center-based, parent-directed and parent-center-involved programs revealed no program in Southeast Kansas even prepares the DD child's parents to contribute to the child's IEP, much less work directly with the child's parent to train the child.

However, all programs said they worked with the child's parents. Our efforts to train preschool and public school special-education teachers and therapists have presented a variety of problems. Teachers find themselves ill-equipped to deal with the heterogeneous group of DD children they have in the classroom, especially at a ratio of ten children to one teacher. When asked to record the amount of time the teacher or therapist has to directly train the DD child in their classroom, the results indicated actual training was limited and ineffective. The continual restating of the same IEP objectives and goals year after year verifies this problem. Many DD programs provide respite for the parents, socialization for the DD child, and another milieu where the child matures at his own individual rate--but little meaningful training.

Have we merely developed and continue to support a failure system?

Our position is simple. For the reasons discussed throughout the paper, we feel that most 0- to 6-year-olds can be most effectively taught by their parents at home. In the case of older delayed children, we also believe that the parents can be more effective educators than can the classroom teachers; therefore, we believe the classroom teachers and parents should work together very closely when setting goals, choosing training techniques, and implementing training. Further, we believe that most current approaches to early intervention and special education (and indeed regular education) actually result in parents adopting the viewpoint, in regard to most education, that "My child will learn that at school." It is our position that over the course of the child's first 21 years, this attitude results in a significant reduction in the number of skills acquired, compared to potential achievements if the parents assume the role of the child's principal teachers. For the variety of reasons discussed in this paper, early intervention and special education teachers and therapists working with the child directly, rather than through the parents, cannot achieve the success that the parents themselves can achieve in training delayed children.

In theory, the provision of educational services to handicapped children that resulted from the passage of PL.94-142 in theory is an important achievement for such children. However, our visits to special education classrooms suggest to us that most handicapped students are not achieving at a level even approximating what we would guess is their potential. For this reason the recent proliferation of traditional, center-based pre-schools in our area frightens us. The recent passage of PL.99-457, and the incorporation therein of such features as a written Individual Family Service Plan (based on the Individualized Education Plan concept), indicates to us that the same systems that we see failing the 4- to 21-year-old delayed students will soon be implemented for 0- to 3-year-old children! This angers us!

As an alternative, we would suggest that early interventionists, special educators, and therapists begin altering their approaches. The models described here and by others (e.g., Perkins & Walter, 1987; Powell, 1982; Shearer & Shearer, 1974) that utilize parents as the child's primary teacher/trainer/therapist, we feel, are superior alternatives. If those professionals currently providing direct services to children will learn and implement the skills necessary to become effective parent trainers and will focus their efforts on developing parent-directed programs, we believe that they will find that they go home in the evenings with a much greater degree of satisfaction!

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The authors want to thank John E. Simmons for his help in preparing the section, "Description of IECIP Services."